Scandinavian Journal of Caring Sciences
EMPIRICAL STUDIES
doi: 10.1111/scs.12283

Caring in an atmosphere of uncertainty: perspectives and experiences of caregivers of peoples undergoing haemodialysis in Iran

Leili Rabiei BS, MS (PhD Candidate)[1], **Ahmad Ali Eslami** BSc, MSc, PhD (Associate Professor, Head)[1], **HeidarAli Abedi** BSc, MSc, PhD (Professor)[2], **Reza Masoudi** BSc, MSc, PhD (Assistant Professor)[3] and **Gholam Reza Sharifirad** BSc, MSc, PhD (Professor)[4]

[1]Department of Health Education and Promotion, School of Health, Isfahan University of Medical Sciences, Isfahan, Iran, [2]Faculty of Nursing and Midwifery, Khorasgan (Isfahan) Branch, Islamic Azad University, Isfahan, Iran, [3]Faculty Member of Nursing and Midwifery School, Shahr-e-kord University of Medical Sciences, Shahr-e-kord, Iran and [4]Department of Health Education and Promotion, School of Health, Qom University of Medical Sciences, Qom, Iran

Scand J Caring Sci; 2016; 30; 594–601

Caring in an atmosphere of uncertainty: perspectives and experiences of caregivers of peoples undergoing haemodialysis in Iran

Background: Chronic renal failure is one of the major causes of mortality and disability worldwide. Although dialysis treatment is considered as a life-saving treatment for these patients, their caregivers face various problems making the atmosphere of caring uncertain.
Aims: This study is aimed to explore and describe the experiences and perspectives of family caregivers of the patients undergoing haemodialysis.
Methods: In this study, 20 haemodialysis family caregivers were selected by purposeful sampling. Data gathering techniques in this research were in-depth and unstructured interview and field observation. The researchers used an inductive thematic analysis approach to analysing the interviews' data.
Findings: Three main themes emerged from the data indicating the patients' care are conducted in a state of uncertainty including *constant struggle to learn*, *effort and adherence to the divine thread*, and *in disease's captivity*.
Conclusions: Caring in an uncertain atmosphere leads to decreased efficiency and quality of family caregivers' care. To promote and improve the efficiency of care, healthcare planners should pay attention to the challenges and perspectives of caregivers of the patients undergoing haemodialysis.

Keywords: uncertainty, caregivers, haemodialysis, challenges, Iran.

Submitted 16 July 2015, Accepted 3 August 2015

Introduction

In recent centuries, the increasing prevalence of chronic diseases and the stupendous costs needed for health care have created critical challenges for healthcare systems (1). Of chronic diseases, chronic renal failure (CRF) and end-stage renal disease (ESRD) are the two main reasons for mortality worldwide (2). The prevalence of CRF is growing in both Western communities and developing countries (3), so that over 1.5 million individuals worldwide are living with haemodialysis or peritoneal dialysis and kidney transplant, which is estimated to double in the future decade (4, 5). In Iran with a population of 80 million, there are over 360 000 patients with ESRD growing at a 12% rate per year (6, 7).

Although haemodialysis is considered as a life-saving therapeutic approach for these patients (8), the patients might later face a variety of requirements and numerous changes in life, which could turn into a heavy burden for their caregivers; adherence to some restrictions during haemodialysis to maintain health could be excruciating for the patients and caregivers, leading to different responses (9). In such cases, the supportive caring role of family members will become clearer, and hence, thinking of haemodialysis patients' family basis as the most important supporter and exploring their requirements is necessary.

Family caregivers of haemodialysis patients are considered as critical agents of both disease management and the patient's quality of life promotion (10). Much care and training is offered to the haemodialysis patients by family

Correspondence to:
Ahmad Ali Eslami, Department of Health Education and Promotion, School of Health, Isfahan University of Medical Sciences, 81746-73461, Isfahan, Iran.
E-mail: Eslamiaa@gmail.com

caregivers. Pressler et al. believe that over 90% of the patients' care is implemented by family caregivers (11). The caregivers assist the patients at various stages of the disease, and the physical, psychological, and mental care is not confined to the advanced stages of the disease (12). On the other hand, it should be remembered that many caregivers report lack of necessary knowledge and skills to support and help their patients and failure to receive adequate guidelines from health professionals, so that they lack satisfactory certainty and preparation to assist (13). In addition, the interaction between healthcare team and family members in hospitals and other supportive centres is not satisfactory, and hence, their need for knowledge and maintenance of health and welfare is compromised (14). Therefore, many caregivers encounter some social isolation and consequently excessive physical stress, disease-caused anxiety and concerns about funding issues and are unprepared to deal with stresses (10).

Compared with other chronic disease, haemodialysis patients' caregivers face a variety of difficulties including patients' repeated admissions to hospital and use of several medicines. They prefer the patients' needs over their own and finally spend less time practicing health-promoting behaviours, possibly resulting in adverse effects on their own health and quality of life (12). On the other hand, if caregivers' needs are not investigated and explained adequately, the patients might be denied of the best services received from the caregivers (12). The need to clarify the factors influencing caregivers, and to reduce caregivers' burden and promote their physical and mental health to improve the quality of life in the patients could be a new area of study on the caregivers of the patients with chronic diseases (10). In a review literature by Given et al., a need for investigations to improve the knowledge and skills of the caregivers of the patients with chronic diseases was observed. However, use of relevant interventions is very important (13).

In Iran's healthcare context, the needs and problems of family caregivers have not been yet addressed satisfactorily and no study has been yet conducted to investigate this issue because of lack of appropriate support and training systems for caregivers in the country (15) and the increased prevalence of CRF. As certain factors including culture and socio-economic status could affect the caregivers' experiences and requirements, this study was conducted to identify and understand the needs and difficulties of family caregivers of the patients with CRF under haemodialysis in Iran.

Materials and methods

Study design

In this study, the descriptive exploratory study design was used. This design is an approach to conducting qualitative research, particularly if there is little evidence regarding the phenomenon under study (6, 16).

Participants

This study was conducted between January 2014 and April 2015 in Isfahan, Iran. Participants consisted of 23 family caregivers. Initially, sampling was run purposefully and then continued theoretically. In Iran's healthcare context, informal caregivers are often spouses, children, parents or first-degree family members who identify themselves as informal caregivers. Inclusion criteria were as follows: age between 18 and 75 years, being main and informal family caregiver (24 hour taking care of the patient and living in their own home), history of several months or over in taking care of haemodialysis patients, providing written informed consent, the ability to communicate in Persian, having patients only with CRF and no other comorbidities, and no other patient needing care in family. The most important reason for exclusion from the study was unwillingness to cooperate at every step of the study.

Data gathering

Initially, the interviews were unstructured starting with the question 'Would you please explain about your experiences of caring for your patient?' Probing questions such as 'Could you say more about that?' 'What did you think then?' and 'Could you please give an example?' were asked based upon the participants' response, to further enrich the information. Eventually, after conducting 41 interviews (2–3 different sessions for each participants), the list of codes was merged into themes, with the analysis continued until all the thematic categories were saturated.

All interviews were recorded by MP3 with permission of the participants and lasted for 45-100 min. To gather the data completely, fieldnote-taking, in addition to recording interviews, was run.

Data analysis

A thematic analysis approach was used to identify the patterns within the text (6, 17). To begin the data analysis, the interviews were transcribed verbatim and reviewed several times exactly so that data immersion was assured. The first author gathered the data through face-to-face interview, the main data collecting tool. Through data collection, the researcher will be able to ask more probing questions in the next interview (18, 19).

Rigor of research

The data were collected from multiple sources (interviews and fieldnote-taking). Each interview transcript

and fieldnote was read several times by the researcher so that a deeper understanding of the data could be obtained. All interview transcripts and list of codes and themes were reviewed and encoded by the researcher's colleagues and compared with the initial coding. Then, some cases of disagreement were discussed and necessary corrections were made. In addition, the initial coding of each interview was returned to the interviewee throughout analysis so that its rectitude could be confirmed and the codes were recognised as valid. Few codes not representing the participants' viewpoints in their own opinion were corrected. Moreover, sampling was run with optimum diversity (diversity in healthcare centres and participants).

The ethical approval was obtained from Research and Technology Deputy of Isfahan University of Medical Sciences (ethics code: 93/2). The participants were informed of the purpose of research and informed written consent was obtained from them. Also participants were assured that participation in the study was voluntary. With the participants' agreement, a room near haemodialysis ward was decided to be the location of the interviews, and during the interview, they were provided privacy and comfort.

Results

Fourteen (78.38%) family caregivers were females and 6 (21.62%) were males, with mean age of 45 years. For marital status, 10 (47.15%) were married and the rest were single. The majority (n = 11 [59.87%]) were housewives. For education, the majority (n = 12 [59.13%]) had diploma education, and most were the spouse (n = 8 [42.85%]) or daughter (n = 6 [28.57%]) of the patient. From the statements of haemodialysis patients' family caregivers, some codes and themes were extracted including three main themes and 11 subthemes. Then, the relevant themes were explained to the caregivers and they could support them.

In disease's captivity

The caregivers of haemodialysis patients often spend a lot of time taking care of their patients in hard and ambiguous conditions such as delayed and/or unclear time of kidney transplant while being in cumbersome and complicated atmosphere, so that the disease holds the caregiver and patient in captivity. The theme of *in disease's captivity* consisted of six subthemes, namely uncertain future, permanent obsession, being in conditions' captivity, frustration, plight and whirlpool of problems, and channel life.

Uncertain future. Experiencing the circumstances when predicting the future of the disease and the patient is not possible, put the caregiver in a situation of confusion and occasional concern. One of the caregivers, in this regard, talked of his experience:

> —I don't know what is going to happen and what incidence happens? This ambiguity and fear of future irritates us further— (Caregiver no. 12).
>
> I've been in waiting list of transplant for two years; it's a mental suffering in the real sense of the word. I don't know my patient will be alive tomorrow or not— (Caregiver no. 4)

Permanent obsession. The participants always talked of their permanent obsession and concern about patients and their problems while caring and thought of it as one of their own bothering mental and psychological concerns. One of the caregivers' experiences in this regard demonstrated:

> —When the dearest family member is sick, then you are always worrying, don't understand night and day, your mind is always involved with [the question] my God! What should I do to make my patient better? Where [can] I take him? Which doctor? Which hospital?— (Caregiver no. 13)
>
> —We most of our time are captured by concerns and obsessions of this disease. We have a fuss and worry about that, God forbid! An incidence may happen that we can do nothing for it— (Caregiver no. 17)

Being in conditions' captivity. One of the hazards threatening patients' caregivers was being locked up in the shadows of the difficulties and problems. The experiences of caregivers indicated that they were always engaged mentally in their patients' suffering and problems so that their routine, daily activities were always influenced by the disease.

> ... I go to work, my brothers and sisters are with mother but I am always obsessed with my mother at work ... (Caregiver no. 10)

Another caregiver recapitulated his experience as follows:

> ... My sister is involved with her own life and my mother has died. Only I follow his affairs. Every week three days I took him [for] hemodialysis. I've lost personal work and life. I missed so much and colleagues complain so much. I can abandon neither my work nor my father ... (Caregiver no. 16)

Frustration. The participants described continuous suffering of the patient and caregiver as the final consequence due to struggling with the disease problems, making them frustrated and depressed.

> ...He didn't get better and sometimes got worse, our nerves are ruined and we suffer ... (Caregiver no. 17)

One of the other participants recapitulated his experience as:

> ... In the past, he was not like this, talked and laughed so much. Now, his conditions are getting worse day to day and no energy has left for us and we got much ruined when we see him like this...

Plight and whirlpool of problems. The disease-related difficulties put the caregivers in a complicated situation, namely captivity in whirlpool of problems. The caregivers stated that no improvement and escalation of patient's conditions led to their hopelessness for the patient's future. Moreover, the suffering tolerated by patient and no response of pain and disease to medicine and treatment occasionally forced the caregiver to yearn for the patient's freedom of this condition and even to feel satisfied with his peaceful death.

> ... At nights he moans and twists so much that I tell myself I wish God give him some belief to feel comfortable [accumulation of tears in the eyes of caregiver], then I say God forbid! It's my father, even for a second life without him has no worth to me... (Caregiver no. 3)

Another caregiver recapitulated his experience as follows:

> ... Treatment and drug can't work for his pain and suffering and he is suffering so much. Recently, he has no sleep; [he] is just hurting so that I'm ready to sacrifice my soul for him ... (Caregiver no. 6)

Channel life. The cumbersome and hard care-related conditions that the caregivers tolerated confined their life, referred as channel life. These conditions forced the caregivers to lose the authority to act and to keep on living with the patients in a cumbersome situation. A caregiver's experience was as follows:

> ...The current conditions of my life are very odd. Even, I can't keep my eyes off her. Traveling and touring and going to park have been closed and all my recreation has become only around the house... (Caregiver no. 11)

One of the caregivers, in this regard, told:

> ...Others tell well! Come to park for your spirit to change but we can't go. My mother is disturbed and feels more comfortable at home. She has no patience of crowd and going out and when she sees that she can't stand up and sit as previously did, her conditions are disorganized so much and I prefer to stay here at home... (Caregiver no. 10)

Permanent trying to learn

One of the most important concerns of haemodialysis patients' caregivers in uncertain conditions is gaining care-related knowledge and information from informal resources. They had to strive to learn in order to advance their care purposes and searched for information under any circumstances, which was naturally suggestive of lack of an inclusive, complete and integrated information system in formal healthcare setting. This theme consisted of two subthemes as follows:

Learning from peers. The caregivers' peers are an informal source of learning. The caregivers, in their care-related experiences, introduced their peers as a source of learning thanks to the similarity of the problem and mutual understanding. Another caregiver told in this regard:

> ... When we come to hospital for hemodialysis, we wait some hours. We sit next to each other and ask each other for many things. Nutrition, weight control, diet and so on. It's also very well because we are comfortable with each other ... (Caregiver no. 12)

As the patients' caregivers spent much time accompanying each other, they managed to have a bilateral, constructive interaction which resulted in the provision of a learning-infused atmosphere penetrating even into home and telephone communications.

> ... In hospital we discussed and debated with each other very much. We sit beside each other in groups and talked about our problems with each other. We have each other's [phone] number and at home we call each other ... (Caregiver no. 12)

Learning through trial and error, and observation. Another learning mechanism to manage disease problems was trial and error, and observation.

> ... For instance, for his body irritation, many times I gave him a meal [and] it's got worse and then I didn't give him that meal. I, on my own, am testing everything to see it agrees with him or not ... (Caregiver no. 8)

Another participant, in this regard, told:

> ... Every time we took [him] for hemodialysis, we learn many things from what nurses do for him. I see what they are doing and I do the same ... (Caregiver no. 4)

Effort and adherence to divine thread

Patient care can be managed by an approach completely different from available ones at a time when there is no certainty of the current situation; remembrance of and reliance on God always comfort hearts. The caregivers, throughout their care-related experiences, raised effort and adherence to divine thread as the key to success, empathy and unity, and continuation of care process. This theme consisted of three subthemes as follows:

Consent to divine Providence. After making many efforts and tolerating much travail during caretaking, the

caregivers consistently emphasised being consent to what God desires and divine Providence. In this regard, a caregiver stated:

> ... when I'm alone I tell God! Let everything that is destined [by you] happen. God! [only] you are Great. Doctor and nurse tell that this disease is chronic and kidneys have stopped functioning but I'm consent to your consent ...

Another caregiver considered toleration of hardships and travails due to a family member's illness dependent on the consent to divine Providence and believed that divine Providence is superior over human's wish, which in turn leads to caregiver's perseverance in fulfilling care schedule.

> ... We are Muslim and always divine Providence and God's universal will is superior over humans' desire, that's why in this abnormal situation of the disease we have stood like the mountains behind the father or all travails... (Caregiver no. 7)

Permanent trust and appeal to the Imams. Caregivers argued that believing in existence of the God who controls the situations greatly reduced situation-related anxiety so that they believed that uncontrollable conditions of the disease could be managed in some way through reliance on and trust to God.

> ... Having meaning and purpose in life for me who take care of my mother is an undeniable principle, feeling of belonging to an eternal and the hope that I have for God's help and assistance in my problematic living conditions strengthens my heart and comforts me much... (Caregiver no. 2)
>
> ... In this plight, the only way I found was appeal to the Imams and seeking for their assistance. We always consider the Innocent Imams as sources of mercy and forgiveness and seek for their appeal. Even, when I took my patient to a shrine or mosque, he got very upset and I, myself, further... (Caregiver no. 4)

Continuity of worry and hope. The caregivers' experiences indicated a continuity of worry and hope throughout the process of caretaking. In fact, the conditions of uncertainty suggest no fixed, managed circumstances of the patients, and fear of and worry about incidence of new problems have been always concurrent with escalation of current circumstances and difficulties. In this regard, a caregiver told:

> ... [The fact] that we don't know what is going to happen and what incidence will happen worries us so much. One day the problem is with his fistula, the other day his pressure goes up and down, every time some problem happens to him and it can't be thought of in advance and managed ... (Caregiver no. 11)
>
> ... We live with him in a way that we are always in [a state of] fear and hope. We don't know what is going to happen. On one hand, he's got dependent on instrument, that is, he should be dialyzed three times a week. In this way, he is bothered so much and we are always afraid of [his] getting worse ... (Caregiver no. 1)

Discussion

In Iran's healthcare context, health caretaking of haemodialysis patients is conducted by their family caregivers in uncertain conditions. The present study indicated that most family caregivers of haemodialysis patients in Iran were female with under diploma education. They were near their patients on average 9 hours per day and took care of them in circumstances such as in disease's captivity, restriction of social cycle, continuous striving to learn, and effort and adherence to divine thread in uncertain conditions.

Caregiver's captivity by disease was a significant finding of the present study. The caregivers' experiences suggested the frustration and captivity due to disease-related problems' complication and difficulties in coping with them as well as tolerance of the permanent suffering of the patent to caregiver, with difficulties and frustration escalating over time. In this line, Chang et al. identified coping strategies and stressful sources in haemodialysis patients and their families. The challenge of concern for and uncertainty of future as well as inferiority is shared by all patients and caregivers in any cultures and healthcare contexts, which is characteristic of the chronic patients undergoing haemodialysis, leading to family's and caregiver's captivity by and surrender to disease (20).

In disease's captivity could be reflected on in similar works, as well. Hagren et al. demonstrated that haemodialysis instrument as a vital way of survival resulted in losing freedom, and being dependent on others and isolated from spouse, family and community. They showed that haemodialysis instrument caused an excruciating pressure for patient's family and social life. In fact, the present study, as with Hagren et al. study, demonstrated denial of independency and hence patient's and family's captivity by disease, because the only way of survival in CRF conditions is dialyser (21).

Hagren also indicated that time-consuming treatment and experience of treatment-associated limitations and repeated referring to healthcare centres increased emotional distance from caregivers and led to family vulnerability. Overall, the present study indicated that participants, in addition to making effort to manage life limitations, considered the disease as violating their time and spatial territory, and healthcare personnel were not

aware of emotional distance from caregivers and the patients' vulnerability (22).

Discovering and explaining care challenges helps caregivers and other health professionals contribute to patients' better living as much as they are able. Polaschek and Kaba argue that gaining experience of taking care of haemodialysis patients gives further insight to offer services to the patients and facilitates satisfactory investigation of their needs (8, 23). An understanding of cultural influences and caregivers' desires could be basis of a comprehensive and culturally holistic nursing care (24).

Generally, haemodialysis patients and their family members need healthcare team's assistance, guidance, information supply and support (25). These patients' caretaking should be inclusive to support the patient alongside family (26, 27). Tackling with the patients' uncertainties ahead and disease leads the caregivers towards frustration. On the other hand, there is no integrated and codified system to support the caregivers in Iran's healthcare context and the caregivers themselves have to strive to answer their questions and remove their concerns, which, if persists, culminates in permanent obsession and excessive confusion due to absence of expertise and variety of difficulties.

The restriction of caregivers' social cycle is another concern derived from the present study. The caregivers, because of being engaged in taking care of haemodialysis patients, consistently affirmed that the disease incidence to a family member led to decline in vitality in and interaction among family members and between them and community. Hagren argues that ESRD shortens not only longevity but also life's width and one has to live a narrow life. In fact, family's whole interactions and communications undergo variations and the caregiver's and other family members' social cycle grew limited and narrow (21). In the present study, consistent with Hagren et al. study, the patients' caregivers interpreted the current conditions as being in conditions' captivity due to the complications and pointed to the intervention of care-related roles in other roles such as working or parenting, being a challenge for giving tactful and comprehensive care.

Ziegert et al. indicated that the changes in life of a patient with chronic disease caused variations in the life of other family members living in the same social and mental setting (28). Family members support each other when one of them acquires a chronic disease, so that they better assist the patient with empathy and utilise supportive relevant sources. But, the present study demonstrated that the caregivers in Iran's healthcare context gradually developed functional restriction due to having no social support preparing them to deal with hard conditions of the disease and sometimes abandoned treatment and care. Hence, the main burden of care was imposed on first-degree relatives leading to restricting family's social cycle. On the other hand, Johnson, Hagren and Polaschek argue that persistent care causes tension and changes in the course of patient's and his family's life, which disintegrates the course of family and social life and hence affects the community (21, 23, 29). These experiences are consistent with those derived in the present study representing the complication of the problems, namely whirlpool of problems, and therefore, healthcare team should support caregivers socially.

Trying to know and gain the knowledge of health care was a serious concern of the caregivers. In this regard, Masoudi et al. have explained the care-related challenges in multiple sclerosis patients' caregivers and demonstrated that the caregivers were always seeking for resources to learn further and offer better care. They reported use of hospital's clinical atmosphere, discussions and debate with healthcare team, and use of internet and TV as their source of learning to give helpful care to their patients and always sought for learning healthcare fundaments (30). Lack of healthcare knowledge of chronic diseases such as multiple sclerosis, haemodialysis, etc. is likely a main concern of health caregivers in Iran's healthcare context, which represents uncertainty.

On the other hand, Baker demonstrated that the caregivers of the patients with chronic diseases usually face a plethora of disease-related information, all of which is general not specialised, which further confuses them because they seek for reliable scientific, practical and updated information to more efficiently take care of the patients. Such information assists them in caretaking by engaging their family members and also supports family relationships (31). These findings confirm our study's findings on the necessity of further coherence and consideration of informational and care-related support for family caregivers. Given et al. also believed that many caregivers lacked satisfactory knowledge and skills and consequently adequate confidence and preparation to take care of the patient and did not receive necessary guidance from healthcare team so that they did not know to play caretaking role, the type and amount of the care required and the supportive source they should use and how to accomplish it (13). The findings of all these studies, in agreement with the present study, indicate the existence of an uncertain healthcare context for caregivers necessitating the development of an integrated plan for empowering caregivers and offering helpful care knowledge to remove uncertain conditions in caretaking atmosphere of the patients.

One of the important findings of this study was the caregivers' effort and adherence to the divine thread to manage the disease-caused problems in uncertain conditions. In Iran's healthcare and cultural context with

predominantly Muslim population, the relation with God is one of the most important elements to resist against problems, especially excruciating problems due to disease, in uncertain conditions. Experiences of caregivers indicated that they consistently paid attention to God to meet the requirements and always sought for his assistance. They believed that an individual in such cases feels no need for others and resists against a mountain of problems. Chang et al. indicated that the effective factor on individuals' capability for adjustment was positive attitude, so that the optimist patients who believed in supernatural power were more capable of resolving the problems (20).

Caixeta et al. also argue that religion is an important supportive element for the patients and God is the best family's shelter in dealing with patient and disease. Caixeta et al. study demonstrated that religion was a route that led them towards churches where recognition of their innocence was achieved. In addition, coping capacity is further developed in them so that they can cope with the disease and reasonably justify and hence accept it. They described spirituality and religion as two rich sources of support and argued for addressing these two in care plans (32). In fact, facing a chronic disease makes the family be engaged in a big challenge and the caregivers and patients always comfort through God's remembrance and consent to his Providence to get free of these problems throughout ups and downs of the disease. In addition, caregivers obtain the richest supportive energy source to take care of their patients by means of trust in God and appeal to the Imams.

Cheraghi et al. believe that spiritual dimension of caretaking influences other dimensions of caretaking and relief caregivers should think of all dimensions of the patients and always consider spirituality, trust in God, and appeal to the Imams as one of the most important components of care (33). The present study demonstrated the spiritual dimension including feeling of satisfaction and peace with remembrance of God and divine Providence as an important promoter of caregivers' ability to take care of haemodialysis patients in uncertain conditions.

Although the study was exploratory and the researchers did their best to enrol the participants from various age groups, gender, economic status, education levels and different healthcare centres, the participants were selected from three public healthcare centres, which could influence the generalisability of data. The present study could act as a basic inquiry to collect useful information, gain insight and generate further research questions. The data obtained may lay the groundwork for more rigorous research in this area such as design empowerment plans and supportive and educative programmes.

Conclusion

The caregivers of haemodialysis patients in Iran take care of their patients in an uncertainty-infused atmosphere. Therefore, development and implementation of interventions to promote the caregivers' knowledge and skills regarding the disease and patient's treatment process is one of the most important duties of policymakers and professionals of health system.

Acknowledgement

This article was obtained from a PhD thesis the Isfahan University of Medical Sciences. Hereby, the researcher would like to extend his sincere thanks to the university's Deputy of Research and Technology for their financial and spiritual support. The researcher also acknowledges with gratitude the contributions and sincere cooperation of patients and their respectable families and all the other centres for assisting in this research.

Author contribution

Rabiei, Eslami, Masoudi and Sharifirad involved in the study conception/design. Masoudi, Rabiei, Eslami and Abedi contributed to the data collection/analysis. Rabiei and Abedi drafted the manuscript. Esalmi, Masoudi, sharifirad and Abedi involved in critical revisions for important intellectual content and administrative/technical/material support. Eslami, Abedi, sharifirad and Masoudi supervised the work.

Ethical approval

The ethical approval was obtained from Research and Technology Deputy of Isfahan University of Medical Sciences for all the four healthcare centres under study (ethical code: 393792). In this study, the participants were informed of the purposes and significance of the research and then the written informed consent to participate in the study was obtained from them. Also, the participants were assured that participation in the study is voluntary and can be discontinued at any time. With the participants' agreement, a room near haemodialysis ward was decided to be the location of the interviews, and during the interview, they were provided privacy and comfort.

Funding

This study has been funded and supported by Isfahan University of Medical Sciences (IUMS); Grant No: 393792. The authors of the present work declare no conflict of interest.

References

1 Nolte E, McKee M. *Caring For People With Chronic Conditions: A Health System Perspective: A Health System Perspective*, 2008, McGraw-Hill International, Shoppenhangers Road, Maidenhead Berkshire, England.

2 Lacasse C, Beck SL. *Clinical Assessment of Symptom Clusters*, in Seminars in oncology nursing, 2007, Elsevier, *Semin Oncol Nurs* 2007; 23: 106–112.

3 Bello AK, Nwankwo E, El Nahas AM. Prevention of chronic kidney disease: a global challenge. *Kidney Int* 2005; 68: S11–S17.

4 Modi G, Jha V. The incidence of end-stage renal disease in India: a population-based study. *Kidney Int* 2006; 70: 2131–3.

5 Grassmann A, Gioberge S, Moeller S, Brown G. ESRD patients in 2004: global overview of patient numbers, treatment modalities and associated trends. *Nephrol Dial Transplant* 2005; 20: 2587–93.

6 Kazemi M, Nasrabadi AN, Hasanpour M, Hassankhani H, Mills J. Experience of Iranian persons receiving hemodialysis: a descriptive, exploratory study. *Nurs Health Sci* 2011; 13: 88–93.

7 Eslami AA, Rabiei L, Khayri F, Rashidi Nooshabadi MR, Masoudi R. Sleep quality and spiritual well-being in hemodialysis patients. *Iran Red Crescent Med J* 2014; 16: 1–7.

8 Kaba E, et al. Problems experienced by haemodialysis patients in Greece. *Br J Nurs* 2007; 16: 868–72.

9 Gordon EJ, Leon JB, Sehgal AR. Why are hemodialysis treatments shortened and skipped? Development of a taxonomy and relationship to patient subgroups/Commentary and response. *Nephrol Nurs J* 2003; 30: 209.

10 Saunders MM. Factors associated with caregiver burden in heart failure family caregivers. *West J Nurs Res* 2008; 30: 943–59.

11 Pressler SJ, Gradus-Pizlo I, Chubinski SD, Smith G, Wheeler S, Wu J, Sloan R. Family caregiver outcomes in heart failure. *Am J Crit Care* 2009; 18: 149–59.

12 Northouse LL, Katapodi MC, Song L, Zhang L, Mood DW. Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. *CA Cancer J Clin* 2010; 60: 317–39.

13 Given B, Sherwood PR, Given CW. What knowledge and skills do caregivers need? *Am J Nurs* 2008; 108: 28–34.

14 Kovacs PJ, Bellin MH, Fauri DP. Family-centered care: a resource for social work in end-of-life and palliative care. *J Soc Work End Life Palliat Care* 2006; 2: 13–27.

15 Pahlavanzadeh S, Ghaedi Heidari F, Maghsudi J, Ghazavi Z, Samandari S. The effects of family education program on the caregiver burden of families of elderly with dementia disorders. *Iran J Nurs Midwifery Res* 2010; 15: 102.

16 Bahrami M. Meanings and aspects of quality of life for cancer patients: a descriptive exploratory qualitative study. *Contemp Nurse* 2011; 39: 75–84.

17 Masoudi R, Abedi HA, Abedi P, Mohammadianinejad SE. The perspectives of Iranian patients with multiple sclerosis on continuity of care: a qualitative study. *J Nurs Res* 2015; 23: 145–52.

18 Birks M, Mills J. *Grounded Theory: A Practical Guide*, 2011, Sage, London.

19 Strauss AL, Corbin J. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*, 2008, Sage, London.

20 Chang S, Lee SJ, Kim JS, Kim SS. Coping of patients undergoing hemodialysis. *Asian J Nurs Stud* 2003; 6: 40–50.

21 Hagren B, Pettersen I, Severinsson E, Lützén K, Clyne N. The haemodialysis machine as a lifeline: experiences of suffering from end-stage renal disease. *J Adv Nurs* 2001; 34: 196–202.

22 Hagren B, Pettersen I, Severinsson E, Lützen K, Clyne N. Maintenance haemodialysis: patients' experiences of their life situation. *J Clin Nurs* 2005; 14: 294–300.

23 Polaschek N. Living on dialysis: concerns of clients in a renal setting. *J Adv Nurs* 2003; 41: 44–52.

24 Davison SN, Simpson C. Hope and advance care planning in patients with end stage renal disease: qualitative interview study. *BMJ* 2006; 333: 886.

25 Wingard R. Patient education and the nursing process: meeting the patient's needs. *Nephrol Nurs J* 2005; 32: 211.

26 Winkler MF, Ross VM, Piamjariyakul U, Gajewski B, Smith CE. Technology dependence in home care: impact on patients and their family caregivers. *Nutr Clin Pract* 2006; 21: 544–56.

27 Thomas N. *Renal Nursing*, 2008, Elsevier Health Sciences, Philadelphia, PA10103-2899, USA.

28 Ziegert K, Fridlund B, Lidell E. Health in everyday life among spouses of haemodialysis patients: a content analysis. *Scand J Caring Sci* 2006; 20: 223–8.

29 Johnson ME. Being mentally III: a phenomenological inquiry. *Arch Psychiatr Nurs* 1998; 12: 195–201.

30 Masoudi R, Abedi HA, Abedi P, Mohammadianinejad SE. Experiences of Iranian Multiple Sclerosis patients' and their caregivers' regarding care and treatment outcomes. *JJCDC* 2013; 3: 21–31.

31 Baker MJ. Education requirements for nurses working with people with complex neurological conditions: relatives' perceptions. *Nurse Educ Pract* 2011; 11: 268–72.

32 Szaflarski M. Spirituality and religion among HIV-infected individuals. *Curr HIV/AIDS Rep* 2013; 10: 324–32.

33 Cheraghi MA, Payne S, Salsali M. Spiritual aspects of end-of-life care for Muslim patients: experiences from Iran. *Int J Palliat Nurs* 2005; 11: 468–74.